### Introduction

- This study explores the journey of obtaining diagnoses and ongoing care for Rheumatoid Arthritis (RA), focusing on patient perspectives, particularly among recently diagnosed individuals.
- The timeline for diagnosis among 33 interviewees ranges from less than a month to over 15 years. Participants highlight the crucial role of Family Physicians (FPs) in RA care, including referral support, symptom management, addressing drug side effects, managing comorbidities, and reproductive health considerations post-specialist attachment.
- Despite their importance, FPs encounter diagnostic challenges, referral barriers, and limited engagement with specialists, indicating the need to address these gaps in RA care access.

# Methodology

- Recruitment sources:
- Arthritis Research Canada's volunteer noticeboard and Facebook groups of ARC affiliates (n=21)
- Clinics affiliated with the Canadian Primary Care Sentinel Surveillance Network (CPCSSN) (n=12)
- Ethical clearance:
- Obtained from multiple universities
- Interview process:
- Semi-structured interview guide developed with input from a national advisory committee of people living with RA
- Piloted for refinement
- Interviews conducted via Zoom
- Duration: 1-2 hours each
- Recorded and transcribed
- Coding process:
- NVivo14® software used for transcription and coding
- Analysis employed deductive coding informed by the Candidacy Framework and inductive coding derived from the interviews.

### Interviewee characteristics

33 interviews (8 Dec 2021 – 25 Nov 2023) • 31 in English, 2 in French

Pan-Canadian: 12 AB, 6 BC, 5 MB, 1 NF, 7 ON, 2 QC

#### Ethnic/religious affiliation: • None (n=22);

- Catholic, Dutch, Quebecoise, German Mennonite, S. Asian (Islamic/Sikh), Scottish, part-Aboriginal, Chinese-Canadian (n=11);
- most indicated limited significance to RA experience.

Gender/sex: 30 female, 3 male

- previous same-sex partners (n=2)
- **Age range: 21-76** • ~30%: 30-39; ~ 20%: 50-59, 60-69; 15%: 40-49, 70-79; 3%: 20-29

#### **Education:**

- High school or less (n=3);
- some postsecondary (n=18); undergraduate degree (n=6);
- graduate/professional degree (n=6)

**Current economic status (self-reported):** • 'comfortable' (n=26); 'struggling' (n=7)

#### Social networks:

- extensive/solid/diverse (n=25); limited (n=8)
- **Community size & nature:** Large-medium city/suburb (n=28)

• small rural/remote (n=5)

- Travel time to FP/rheumatologist (greatest):
- 30 mins or less (n=23)
- 30+ mins-1 hour (n=6) more than 2 hours (n=4)
- Time since diagnosis with RA:

#### • less than 5 years (n=25)

- 6-14 years (n=5) more than 15 years (n=3)
- Time to secure a diagnosis:
- less than 1 year (n=16)
- 1-2 years (n=6) more than 3 years (n=11)

### Reference

Medical Research Methodology. 2006;6(35). doi:10.1186/1471-2288-6-35

#### Dixon-Woods M, Cavers D, Agarwal MS, et al. Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. BMC

# Accessing Care for Rheumatoid Arthritis: The Role of Family Physicians

Koehn, S., PhD<sup>1</sup>; Klein, D., MD, FCFP, MSc<sup>1</sup>; Jones, C.A., PT, PhD<sup>1</sup>; Barber, C., MD, FRCPC, PhD<sup>2</sup>; Jasper, L., PT, PhD ; Pham, A., MD, PhD<sup>1</sup>; Drummond, N., PhD<sup>1</sup>.

"At one point I thought I was losing my

mind and started keeping a journal. They

put me on Prozac, like, pretty early on,

because I think they thought I had

anxiety, right?" (Karla)

**Emotional Impact** 

**Emotional challenges are** 

common, emphasizing the

need for holistic approaches.

"I had so much pain I couldn't even pick

up my baby. I was very depressed – I

should have got some psychological

"Waiting to see a rheumatologist that

long [3-4 months] is unacceptable when

you're in pain that is nearly suicidal."

(Jacqueline)

help, but I didn't. I wish I had." (Angie).

<sup>1</sup>University of Alberta, <sup>2</sup>University of Calgary

"I've [had 4 GPs in 8 years], and it gets tiring because you're with them for 2, maybe 3 years, and then they're gone. ... You have to apply [to the new doctor]. But last replacement took us almost 2 years. We had nobody up there, so if we needed a doctor we could go to a walk-in, but they only accepted so many walk-ins 3 times a week. [They're] so backed up, too. ... Right now, we're booking 3 months ahead [to see the GP]." (Elsie, in a remote northern community).

### **Systemic Challenges**

Healthcare system challenges include bureaucratic obstacles and long wait times.

"[Humira works but] it's like \$2600 or more per box of three shots. But the [insurance] won't pay for it. I mean if I go through all of the biologics then they will go, OK she's tried everything we will put you back on Humira. So yeah, they're guinea-pigging me all the way with it, right? Because of expense." (Robyn; also John).

Diagnostic Challenges

Patients often report seeing multiple healthcare

providers before they secure an RA diagnosis and

are often misdiagnosed in the interim. Diagnostic

processes involve diverse approaches, including

tests and referrals, and these multiple points of

contact can add time to the process, but don't

always provide conclusive results.

"A specialist for hands ... wanted to do surgery,"

because at this point, they were still saying it was

Trigger Finger [but] ... because I was having all

these other symptoms, I was a little apprehensive

about that, and I continuously was having

problems starting up. ... So I think I just started to

feel very defeated, because I have gone to all

these doctors and gone to specialists, and not

really getting any answers" (Karla)

**Diverse Onset and** 

Manifestation

RA symptoms vary widely, from

joint pain to systemic issues, and

these diverse initial manifestations

may make it challenging to present.

"With fatigue, I actually thought

it was depression that I was

experiencing" (Eileen)

"[A resident

and my GP]

did blood work

... X-rays...

manipulation

of my knees

and my ankles

and whatever,

... then they

came up with

Polymyalgia"

(Yvonne)

"I just kept thinking I

had a broken finger

that wasn't healing"

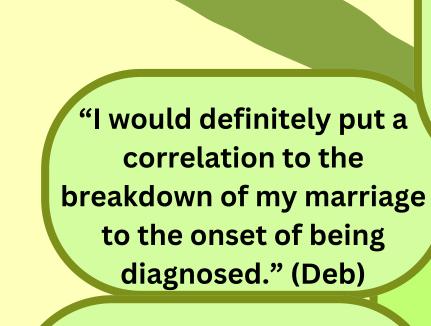
(Jenny)

"It was no matter

where he touched me, I

was in pain. ... It was

everything" (Robyn)



"I had to give up breastfeeding my baby to be on that drug, so I was really really distressed – it was a lot all at once." (Angie)

"I would have liked more people asking me about like does the arthritis ever prevent you cooking? Does it ever prevent you walking? Does it ever prevent you socializing? 'cause it started doing those things well before I mentioned it." (Lisa)

### Impact on Daily **Life and Work**

**RA** significantly impacts daily life and work, requiring collaborative efforts.

"There is no such thing as financial stability as long as you have RA because you'll never know when a medication will fail or when a flare will keep you from working." (Clara, selfemployed)

"I also do occasionally see a massage therapist, but again, it's a referral that I asked for. ... It hurts a lot when I'm sitting there, but it feels great after.... I always wonder if I didn't advocate for myself. Like, what happens to all the people who don't know how to advocate for themselves?" (Jenny).

### Communication and Advocacy

**Effective communication with** healthcare professionals is crucial. Proactive communication and selfadvocacy are common threads.

"Write down your symptoms, take pictures of the swelling. Tell them how it's affecting your life on a daily basis, because that's I think that's the key part. ... Try to condense it. ... That's speaking a language that people can understand and be more empathetic to as well." (Clara)

Funded by the Arthritis Society of Canada, Award # 20-000000018

### Conclusion

- In navigating the complex trajectories to a diagnosis and care for RA, family physicians emerge as key orchestrators.
- Diverse patient experiences underscore the crucial role of family physicians in recognizing symptoms, facilitating timely referrals, and maintaining open communication.
- The challenges and obstacles revealed highlight the importance of family physicians adopting a comprehensive and patient-centric approach.
- A collaborative patient-doctor relationship underscores the significance of empathy and attentiveness in family physicians when managing RA
- As primary points of contact, family physicians are pivotal in coordinating care and providing holistic support to individuals navigating the intricate landscape of RA diagnosis and management.

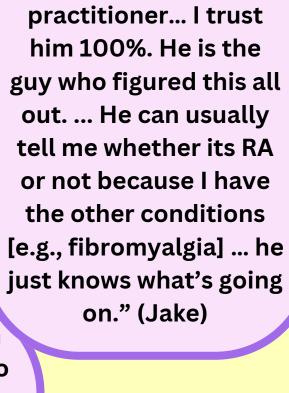


"[My family physician] was really helpful last year when I was going back to work [after maternity leave] and I was still having really significant symptoms and she was able to help advocate for some modified hours on my return, and she provided for the support for that." (Kelly)

# **Patient-Doctor** Relationship

A supportive patient-doctor relationship is pivotal in the healthcare journey.

"I'm thankful for that relationship with my family physician [who] ... was able to advocate to get me into an appointment [with a rheumatologist 2 ½ months] sooner to get some management on board 'cause it was clearly needed." (Kelly)



"My general



## **Treatment Challenges** and Adjustments

RA treatment involves various medications with trial-and-error adjustments to balance efficacy and side-effects.

"I still can't tolerate [methotrexate]. I call it rat poison. It's terrible stuff, I take it, but it causes acute nausea, and every week I deal with that. But am on a bunch of other stuff to to keep everything at bay." (Jacqueline)

"So [my family doctor] will prescribe me Prednisone as needed and she'll write out a few refills for me. ... My rheumatologist doesn't like that I still use the Prednisone because it is bad for you. I'm aware of that, but you don't live in my body. ... The pain got so bad that I was contemplating some bad things, so if this keeps me away from that scenario, I'm gonna do what I have to do." (Kira)







